Title Page

Title: Models of Peer Support to Remediate Post-Intensive Care Syndrome: A Report Developed by the SCCM Thrive International Peer Support Collaborative

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Abstract

Objective: Patients and caregivers can experience a range of physical, psychological, and cognitive problems following critical care discharge. The use of peer support has been proposed as an innovative support mechanism.

Design: We sought to identify technical, safety and procedural aspects of existing operational models of peer support, among the Society of Critical Care Medicine Thrive Peer Support Collaborative. We also sought to categorize key distinctions between these models and elucidate barriers and facilitators to implementation.

Subjects: 17 Thrive sites from the USA, UK, and Australia were represented by a range of healthcare professionals.

Interventions: Via an iterative process of in-person and email/conference calls, members of the Collaborative, defined the key areas on which peer support models could be defined and compared; collected detailed self-reports from all sites; reviewed the information and identified clusters of models. Barriers and challenges to implementation of peer support models were also documented.

Results: Within the Thrive Collaborative, six general models of peer support were identified: Community based, Psychologist-led outpatient, Models based within ICU follow-up clinics, Online, Groups based within ICU and Peer mentor models. The most common barriers to implementation were: recruitment to groups, personnel input and training: sustainability and funding, risk management and measuring success.

Conclusion: A number of different models of peer support are currently being developed to help patients and families recover and grow in the post-critical care setting.

Introduction

Physical, cognitive and psychological problems are common among survivors of critical illness and are often associated with a reduced quality of life (1-4). This constellation of physical and psychosocial consequences of critical illness has been termed Post-Intensive Care Syndrome (PICS) (5-6). These issues are also seen in the caregivers of survivors (7-9). While some in-ICU strategies to prevent PICS have been proposed (10-12), current strategies aimed at reducing PICS and Post Intensive Care Syndrome- Family (PICS-F) do not eliminate the problem, warranting additional intervention to treat the condition (13-17).

Peer support has been proposed as a novel intervention to help support recovery following critical illness (18-19). Peer support is the '*process of providing empathy, offering advice, and sharing stories between Intensive Care Unit (ICU) survivors. It is founded on the principles that both taking and giving support can be healing, if done with mutual respect'* (18). Peer support is hypothesized to act by building social relationships that have a reciprocal influence on health and well-being, as shown in patients with cancer and depression (20-24). Peer support strategies may also offer emotional and social benefits for both patients and caregivers (25). At present there is data from other specialties, which describes the beneficial impact of peer support on recovery and self-management (26).

There is limited information on the influence of peer support in critical care recovery (26-27), and very little description of what is being done under the broad rubric of "peer support" in the field. We sought to provide the first systematic approach to identify technical, safety and procedural aspects of existing models, categorize key distinctions between these models, and elucidate barriers and facilitators common across models and specific to each model.

Methods

Study Context

This work was developed as part of the Society of Critical Care Medicine's (SCCM's) international Thrive Peer Support Collaborative. This Collaborative brings together critical care clinicians and researchers using hospital-based peer support models, to improve patients and caregiver outcomes after critical illness. It was advertised internationally and recruited new members in 2015 and 2016 through the SCCM as well as in international meetings. SCCM offered a $5,000 grant to hospitals with a functioning or start-up ICU peer support group. During the selection process for the collaborative, diverse models were actively sought, and such diversity was prioritized during selection. Active and planned peer support programs were eligible for inclusion. No formal metrics were used to quantify diversity at the time.

This project was reviewed by the Chairman of West of Scotland (UK) Research Ethics Committee as well as by the University of Michigan IRB, who agreed that this work was not subject to ethics approval. All members of the Collaborative agreed to share their experiences in this manuscript form.

Study Design

To investigate the value of peer support as a mechanism for recovery, a systematic line of research is necessary to compare and refine diverse approaches. The IDEAL framework provides a structure for the evaluation of complex interventions. Developed by a multi-professional team of clinicians and methodologists, the framework started as an evaluation technique for surgical innovation. It is suitable for interventions which require the development of technique, which are not immediately suited to a traditional pharmacologic-model of Randomized Controlled Trials (RCTs) (28). The IDEAL framework is a five-stage process: Idea (Stage 1), Development (Stage 2a), Exploration (Stage 2b), Assessment (Stage 3) and Long-Term Study (Stage 4) (28).

Utilizing the IDEAL Framework, this paper is early Stage 2a study of post-ICU peer support. Stage 1 reports have been published in this area previously (29-31). Stage 2a aims to systematically report on multiple sites' approaches to this problem. The focus of this stage is on technical, safety and procedural successes and barriers. The IDEAL Collaborative framework argues that such 2a studies form an essential basis for well-designed systematic registries (Stage 2b) and subsequent evaluative RCTs (Stage 3) (32).

At the October 2016 in-person Collaborative meeting, group sessions defined key areas on which the peer support models could be compared (Figure One). Follow-up interviews were conducted by a leader in the initiative (JMcP). These interviews sought clarification of the information discussed at the in-person meeting. They represented informal discussions with different site leads.

A subgroup of the Collaborative members reviewed the information generated and identified clusters of models; the results of this assessment were reviewed by the entire Collaborative for member-checking and feedback and refined iteratively via email and conference call (33). A subgroup of Collaborative members then identified a candidate list of common barriers and facilitators; these were also proposed to the entire Collaborative.

For the purposes of this evaluation a caregiver was defined as the individual who provided the majority of the financial, emotional and physical support for the patient or the individual primarily responsible for caring for the patient on an unpaid basis (34).

Results

There were 17 sites actively working to provide peer support as part of the SCCM Peer

Support Collaborative between October 2016 and July 2017. Six general models of peer support were identified, based on combinations of timing (in-ICU, immediate post-ICU, or any point); leadership (purely patient, mental health professional, or ICU clinician); and location of services (at hospital, elsewhere in person in the community, or online). The following section will describe each model type.

Community Based Model: Meetings are led by both former patients and/or staff; community-based support groups offer former patients and their caregivers the opportunity to discuss their critical care experience and ongoing recovery. These groups can be a mixture of patients and caregivers, patients only or potentially caregivers only. In general, the time frame in which participants are specifically invited to these groups varies across the Collaborative. Community based groups invite participants in the months following critical care discharge, however, offers of invitation are usually open-ended and participants attend when they feel is appropriate for their recovery. These groups take place in a variety of environments including community halls, churches and coffee shops, but can also be offered within the hospital setting. A wide range of topics, directed by participants, can be covered (Supplemental Table One). The number of participants attending varies, with numbers ranging between 12 and 20 participants per group. An example of this type of group within the collaborative is at Guy's and St Thomas' Hospital (UK).

Psychologist- Led Outpatient Model: The defining feature of these programs is that they are guided by psychological principles with the aim of sharing and normalizing experiences. This model often has a process-oriented focus. Another characteristic of this model is that more experienced participants often support new members of the group. Facilitators with formal mental health training scaffold this dynamic. Internationally, the number of participants attending these groups tends to be less than 10. One of these groups have been set up in consultation with the broader UK program ICUSteps (http://www.icusteps.org) which is not institutionally affiliated with Thrive. Psychologist-led peer support groups are similar to the Community Based Model and are in use in Vanderbilt University (USA), University College London (UK), and Intermountain Medical Center (USA).

Models based within ICU follow-up clinics: Peer support can be implemented within post-ICU clinics and programs, often through use of waiting areas where patients and caregivers are given the opportunity to meet others in an informal setting. This gives the opportunity for intentional, unstructured peer support. Individuals further along the recovery trajectory also intentionally attend to offer informal support and advice. Across the collaborative, approximately 10-12 patients will attend these clinics at any one time. An example of this model is the InS:PIRE (Intensive Care Syndrome: Promoting independence and Return to Employment) program, which is run in Glasgow Royal Infirmary (UK) (30-31).

InS:PIRE is operated on a cohort basis for patients and their caregivers, 6 to 12 weeks after hospital discharge. It is facilitated by a multi-disciplinary team as well as former patients and caregivers who are further along the recovery trajectory. Peer support is intentionally fostered within this program when patients meet each other in the social café area (unstructured peer support) which is used as their waiting area for appointments. These "more senior" peers offer information, advice, and encouragement. There are also group sessions run by the physiotherapist, psychologist and various community organizations (structured peer support).

Online Model: Utilizing dedicated websites (or forums) to provide support for survivors of critical care is another potential model, with some positive benefits of this approach being reported in other specialties (35). This model can be operated by hospital organizations, or led by patients and caregivers. In a bulletin board model, individuals register (without necessarily using their real names) and post responses to existing questions or comments. They can also start their own thread. Anyone, registered or not, can read the posted comments—this is made known to all. Private conversation is also possible. A moderator approves comments prior to posting, to ensure civility and appropriateness; the moderator also posts links and poses questions in order to generate interest. Interaction is staggered in time, rather than being real-time back-and-forth. Other online models have also been used to host electronic meet-ups, where discussion can occur in real-time; one such group has been developed by an SCCM staffer and patient's outwith a Collaborative site (https://www.facebook.com/ThriveICU/). Clinicians participating do not offer formal medical advice or consultation. The Mayo Clinic are currently utilizing a online bulletin board approach.

Group Based Model based within ICU: This model is operated by staff within the ICU and is predominantly aimed at caregivers. Participants are invited during the ICU stay, with the aim of fostering support; they can attend at any point during the hospital stay. Although currently aimed at caregivers, this model has the potential to develop along the recovery trajectory. Similar to the Psychologist-led model, there are usually less than 10 participants at these sessions. One such support group is currently running in the Tennessee Valley Department of Veterans Affairs Hospital (USA). This support group runs weekly in the hospital and is facilitated by a social worker and Chaplain. Those in attendance direct the topic of each group with sessions, lasting between one to two hours.

Peer Mentor Model: This model of peer support, which has been tested in other specialties such as diabetes, is currently being explored across the Collaborative (36). Teams within the Collaborative are looking to link individuals who are further along the recovery trajectory with patients who are still within the hospital environment. The aim is to create

a formal support mechanism for the recovery period. Recruitment and risk management strategies are particularly important within this context and are being fully investigated before commencement of this system. Tennessee Valley VA Hospital (USA) and Glasgow Royal Infirmary are developing these models.

Supplemental Table Two details additional aspects of the models which have been explored across the Thrive Collaborative.

Barriers and facilitators for implementation

None of the programs described had easy formation experiences. Common barriers included: recruiting participants, ensuring adequate personnel input and training, sustainability and funding, risk management strategies and measuring success.

Recruiting participants: While there are large numbers of ICU patients with new difficulties after critical illness, these patients do not necessarily see that these issues are related to their ICU stay, at least not at post-critical care discharge. Fundamentally there appears to be a lack of awareness of PICS and as such survivors are not necessarily attending clinical services that might benefit them. Moving forward, energy must be placed on raising the profile of PICS and survivorship from critical care, to ensure that patients and the wider public, have an understanding of the difficulties faced by this group.

Recruitment strategies across the Collaborative varied, but tended to be based on the structure of the intervention. Follow-up clinics used standard hospital appointment schedules for involvement if the peer support program was integrated with their clinic. Community-based, psychology-led models and models based within ICU used strategies such as *(1)* In person visits to patients' rooms while in the acute phase of recovery; *(2)* posters within the hospital; *(3)* discussions at follow-up appointments and formal referrals from healthcare professionals; and *(4)* invitations to research participants at programs with robust post-ICU research. All programs implement reminders for participants, given the high incidence of cognitive problems following critical illness, including email reminders, text alerts, and phone calls. Center's also used early discharge planning meetings to highlight peer support programs. At present, due to the wide range of techniques utilized to recruit patients to these groups, it is difficult to ascertain the most successful elements of recruitment strategies and more difficult still, to measure this success.

Personnel input and training: Adequate training was felt necessary for both volunteers and staff involved in the delivery of models of peer support. Some engaged moderators who had experience of peer support techniques.

Sustainability and Funding: Within the UK NHS, ongoing post-discharge care of ICU patients is now a standard of care (37). Despite this, in the UK and overwhelmingly in the USA and Australia, support following ICU discharge was being facilitated by donated time. Critical care providers reported that their job descriptions did not contain dedicated time for follow-up. Dedicated time to conduct the peer support programs is a challenge. Within our group, dedicated time has been reported in selected sites within the United Kingdom.

Risk Management: Institutions in the US raised concerns about potential liability being incurred. Concerns included whether malpractice insurance policy would cover practitioners not physically in the hospital or outside their normal scope of practice (e.g. an intensivist discussing follow-up). In general, a 'common sense' approach to risk management, with constructive engagement and some forethought regarding risk assessment of patients, was adopted by many members of the Collaborative. This common-sense approach ranged from ensuring that 'high risk' patients were assessed before attendance at meetings, to ensuring that more than one member of staff was present at all times to allow for individual support if necessary. Further, hospitals had developed formal approaches to involving and training volunteers and have found that having potential peer leaders go through such a program, provided adequate training and institutional buy-in to allow the program to proceed. Regarding the issue of malpractice insurance coverage, some institutions have come to the conclusion that peer support activities would be fully covered, whereas others have had concerns; we are unaware of any case stemming from peer support that would provide definitive legal guidance.

Measuring Success: There was no consensus as to how to measure success of peer support or what metrics would be the most effective for administrators, in order to justify continued funding. Some argued that sense of hope and engagement could be utilized as a measure of success. Others use attendance at meetings as a metric, as it may represent patient-perceived value. One site was undertaking a formal study to assess social outcomes such as return to employment and concepts such as self-efficacy. Finally, two programs were instituting personal goal setting for patients who attend peer support, similar to other rehabilitation programs (31,38).

Discussion

This IDEAL Stage 2a study of an international Collaborative of peer support programs demonstrates six distinct structural models, motivating ongoing efforts to provide peer support to survivors of critical illness. These six models had not been clearly delineated in past work in peer support in this population, and several have not undergone any formal

evaluation despite the fact they are already being used in patient care (26). This study further demonstrates at least the initial viability of peer support programs, with models operational on at least three continents. All programs experienced common barriers to their development—particularly recruiting participants, ensuring adequate personnel input and training, sustainability and funding, risk management strategies and measuring success—which need to be systematically addressed in order for programs to succeed.

Peer support bears similarity with the problems faced in evaluating surgical innovation. In particular, a critical issue is that many quite diverse things can be done under the label of "peer support". Yet any meaningful evaluation must have an approach to defining what specific techniques are being used, and for comparing and contrasting models to systematically accumulate experience and evidence going forward. Therefore, we have drawn on the framework of the IDEAL Collaboration to guide this program of research. Having conducted an IDEAL Stage 2a study to define clear models and how they vary, the next step of this work is to begin systematic registry studies and small refinement trials.

It is important to acknowledge that there is currently no proof of the effectiveness of peer support in the ICU survivor population (26). However, there is no clear reason to suspect this approach would not work with survivors of critical illness, given its demonstrated effectiveness with other populations (39-41). This study suggests a number of issues should be considered in the design of future research. This includes, but is not limited to, the need to carefully consider the context and to define the primary goal of peer support and thus the most relevant patient-centered and testable measure of success. By understanding these issues, efforts can be streamlined and a landscape for future research laid.

For early adopters of post-ICU peer support, initial barriers include that many patients do not necessarily identify their problems as rooted in their critical illness. There is also often a lack of institutional support. These barriers have not proven insurmountable. In systems with a population-health perspective, from the UK National Health Service to the US Veterans Administration, but also growing numbers of hospitals in the USA, the possible post-discharge benefits of peer support may be seen as sufficiently compelling to warrant investments. The investment to sustain peer support may plausibly be less than that required to sustain intensive nurse directed follow-up such as after congestive heart failure, for example (42).

We envisage that future research around peer support in critical care should focus on three key areas: optimizing recruitment for programmes; the development of effective and appropriate outcome measures for both patients and healthcare providers and finally, the efficacy of each particular model.

This early Stage 2a study has a number of limitations. Consistent with the framework stage, we provide no efficacy data; instead we provide a base for future research. We have not enumerated all possible models of peer support. No national registry of peer support programs is available (43). Instead, we take advantage of a unique international Collaborative to identify a number of operational models that can be a base for future work and note that only a subset of possible combinations of timing, location, and leadership have been made operational. Lastly, there are no longitudinal data on long-term sustainability, as all models are in their infancy.

Conclusion

Different models of peer support are currently being developed to help patients and families recover and grow in the post-ICU setting. These have been implemented despite recurring difficulties. An initial typology of peer support programs into one of six categories has been proposed which can help standardize future reporting, help define more meaningful outcome measures and springboard the development of future research.

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